

**MEMORIES AND GRATITUDE OF A CONGENITAL
BLUE BABY**

by
Anthony Joseph Nagy
Born May 2, 1941

**Dedicated To The Family Who Nurtured And Protected Me and To
The Medical Community That Allowed Me To Heal And Live**

Submitted To
**The National Institute of Health
National Library of Medicine
Bethesda, Maryland
March 19, 2009**

I started writing this on February 6, 2009. How pertinent, since today commemorates National Heart Disease Awareness for Women and the whole month is dedicated to Heart Disease Awareness. In fact, an agenda item for a City Council Meeting in Arlington Texas, where I live, honored a young child who had had a plugged pulmonary valve which was corrected in utero. What a difference from my story. When you read this memoir, remember that a lot of water has passed under the bridge in the nearly 68 years I have enjoyed life on this earth. Many of my memories are interpreted and expanded upon by what I have learned in the past 50 years about myself and my childhood illness.

I was born in the late spring of 1941 in Trinidad, Colorado. My mother had been ill during her pregnancy; whether that had anything to do with me being born a blue baby, I will never know. The family doctor (Dr. Eugene Pfile) who delivered me recognized my problem and told my mother to take me home and enjoy me for whatever time I had to live. I didn't know I was sick with a congenital heart defect, but my family did. They knew it was serious, but I doubt they knew the details. Later I was to find out I had a restricted pulmonary valve and a hole between the chambers of my heart.

My earliest memories of my childhood are of standing in the front seat of a car waiting and watching as trains filled with trucks, tanks and people passed by. There was a war on. I didn't know what that meant but I do remember the meat market we went to and the books of ration stamps that we had. Later I remember we didn't go anywhere in the car anymore. I didn't know then what I know now, that there was no gasoline for the car. It was the era of the movies, and I remember being carried in the cold and snow as my family took me to the movie theater that was just down the hill.

Let me say a few words about my family, without whose help I would not be writing this. My parent's marriage was not successful and they were separated before I was born. My mother's family took us in. My maternal grandmother, my mother's older sister and husband, my mother and I, and a bulldog named Spot lived together in a rented house. I remember the bulldog, and my mother throwing my bottle of milk out into the yard in frustration because, after a couple of years, I was still wanting the bottle. Later on, she laughed about it because I put up such a fuss that she had to retrieve the bottle that Spot was licking and enjoying. She was so angry she didn't wash the bottle either.

In about 1947, my mother worked for a land title company and heard about a house being sold for back taxes. As I went through my mother's papers after her death, I learned that the house was purchased for a little over \$700 dollars. She and my aunt and uncle purchased it, and we all moved in. My aunt and grandmother took care of me while she was at work. My uncle played ball with me and let me use his tools in the garage to occupy my curiosity. The memories of this house at 515 South Maple Street are still with me. The best memories are of lying in the warm sun that came through the dining room window and the staircase that tempted me to slide down the banister. My grandmother was feisty, but she did take the time to teach me to tie my shoe laces – I remember it like it was yesterday. She spoke mostly Italian, but I understood when she had lost patience with me.

I was still unaware that anything was wrong with me. That didn't happen until I started school. The first and second grades were not bad. I liked school, but then my friends noticed I was different. Why were my lips and skin so dark or blue, they would ask? I didn't know how to answer. Then my family started telling me that I could not do what the other children did – like riding a bicycle or running or even climbing stairs fast. I wanted to play the trumpet, but my mother said no. She said it would be hard on me. I didn't understand, but I did start playing the piano. The biggest hurt came when adults would ask what was wrong with me, and comment on how blue my lips were. I came to dislike the color blue. I didn't want anything blue and never wore anything blue. My family favored red for me. How appropriate; that's the color women are asked to wear today in support of heart disease awareness.

When I was about 11 years old, my mother heard from our family doctor, yes the one who delivered me, that there might be something to help me. He recommended a pediatrician in Pueblo, Colorado (Dr. Ted Miller) who in turn recommended a cardiologist at the University of Colorado Medical Center in Denver, Dr. S. Gilbert Blount. He was a big man and talked with an accent. He told me he had come to Colorado from Johns Hopkins in Baltimore. I didn't have any idea where that was, but I know now that Johns Hopkins is where the procedures for my ultimate cure had their beginning. That is an interesting story in itself, but I leave it for you to discover.

Over a period of several months, Dr. Blount and friends looked at me, listened to my heart, and evidently told my mother there was hope that something could be done. I was not only happy that things would change and I might not have to put up with the teasing and bullying anymore, but I got to eat at restaurants and stay in a hotel when we went to Denver to see Dr. Blount. I also didn't mind the pain of the catheters that were routed through my blood vessels to measure the pressures within the heart itself. I didn't realize that I would be serial number 1 in what was then experimental surgery that was on the cutting edge (no pun intended).

Dr. Blount was teamed with a surgeon who I only knew as Dr. (Henry) Swan. I don't remember any particular encounters with Dr. Swan. I just remember he was the one who could make me well.

The Christmas of 1952 is memorable to me. It was the Christmas I received my electric train. I had wanted an electric train and I knew they were expensive. I was still young enough to believe in Santa Claus. I received the train out of what I now realize was the love showered with the realization that I might not have another Christmas. I was of course oblivious to this reasoning then. I still have the train and occasionally, at Christmas, I take it out of its well-preserved boxes, put it together, and run it for awhile. It has fond memories for me.

January 8, 1953, was the date of my first surgery; it was also my aunt's birthday. I checked into the hospital a day or two before, not knowing what to expect. My memory is hazy, except for the recollection of the ward being a very unfriendly place. I remember a girl patient in the ward who tried to boss everyone around; funny how some memories never fade, especially of bullies.

I didn't like hospital food, so my family brought hamburgers for me to eat. I loved hamburgers. If I recall correctly, there was a drug store on a corner near the hospital, Hatch Drug, where the hamburgers were purchased. I can't find any information now to confirm my memory, but the name came to me as well as a picture in my mind of it being on a corner near the hospital. I was told that I would be put in a tub of ice for the surgery. I

couldn't really understand this, but I really didn't care. I was looking forward to being normal.

It was cold in January and the hospital was cold; maybe it was the ice bath. I awoke in pain and was getting a lot of medicine. I was in a tent – an oxygen tent, I was told. I had a tube stuck in my side that ran to a jug on the floor. The doctors came around early in the morning, always in a large group. I didn't like the food and I looked forward to the hamburgers for the evening meal that my mother and family brought to me. I don't think I was in the hospital very long. I don't remember the exact day I was allowed to leave, but I do remember being in the back seat of the car traveling the 200 or so miles back home to Trinidad.

My chest hurt from the surgery. The incision went from under my left arm to the center of my chest. I would later be ashamed of this scar because of the questions it prompted about what happened. I still wasn't cured. I was still blue or cyanotic as I heard it called. I was told that there was not enough time to do all that was required, but with what was done, the other problem (the hole, or septal defect) might cure itself.

We lived in a two-story house and the bedrooms were upstairs. My uncle carried me upstairs on his shoulders in the evenings for a month or two. That was fun, because I could touch the ceiling going up the stairway. We went back to Denver for checkups, but I was back in 4th grade with my friends and doing alright. I still could not walk to school and had to watch my exercise, but I was still ornery enough to get a spanking once in awhile.

The next few years of my life were not very happy for me. My mother decided I had to go to a different school because, the school where all my friends were had the 5th and 6th grades up several flights of stairs. I didn't quite understand, but later I realized that my family was taking care of me. They didn't want me to exert myself climbing the stairs. I still wanted to play the trumpet, but instead I did a one year tour on the violin. I still would recognize the smell of rosin, but I haven't touched a violin since.

I was back with my friends in 7th, 8th, 9th, 10th, and 11th grade. I grew up to like girls and cars. My first job was cleaning windows at a jewelry store; I soon moved on to the

higher paying job of sweeping floors. I waited very impatiently to get my driver's license. At age 16, I helped a friend overhaul his 1948 Chevrolet. I routinely went to the doctor for tests, and still had blue lips. I could go on about my teen years, but you understand because you went through yours too.

During these years, the hope that the hole in my heart would heal itself slowly slipped away. I had come to realize that the hole was not healing by itself. The doctors also hoped, but gave up too. Again, we were back and forth to Denver for additional tests, There were several catheter tests spread out over time, two in the elbow joint and one in the groin. I will always remember these procedures as they were done under local anesthetic and I was awake. The one in the groin really hurt and it was eerie to feel the catheter finding its way into the heart – sometimes taking an intended or unintended path, being pulled back, and pushed once again.

There were many tests done in a darkened room behind the screen of the Fluoroscope drinking foul tasting chalky material. People surrounding the screen wore leather looking aprons. I was curious as a teenager and found out why the aprons were so heavy; they contained a lead sheet to protect the observers. I wondered about my own well-being, since I was the one behind the screen. Evidently nothing too bad occurred since I am able to tell you about it.

Electrocardiogram tests were many. The machine was the size of a refrigerator with thick chords attached to your body; the skin was rubbed raw by a tongue depressor to achieve good contact where the electrodes were attached. The worst part was the rubbing of the skin with the wooden tongue depressor. I really disliked electrocardiograms, but they have greatly improved in the past 50 years, no more rubbing the skin raw.

It was hot in August of 1958 when I entered the hospital for my upcoming surgery, but I wasn't afraid. I was looking forward to my senior year in high school. I don't remember much except the coolness of the oxygen tent after the surgery and the heat of the room when it was removed. I was told Dr. Swan performed the operation with his leg in a cast, because he had been in an airplane accident.

The reason I don't remember much is because several days had passed before I woke from surgery. I had been in a coma and had experienced grand mal seizures. I remember my family being at the bedside when I woke up. I couldn't talk because I had a tracheotomy and I was told the only way I could talk was to cover the hole in my throat with my finger. None of the medical staff seemed to be sure of why I had seizures. I had been given a blood clotting drug before surgery because I was a "bleeder". I found upon waking that I was being given the blood thinner heparin. I was getting shots in the rear end and blood was being taken from the arm to test blood clotting time. This exercise was to cover the possibility that I had a clot or "thick blood" go through my brain and the blood thinner was preventative. Some thought that an air bubble had gotten into the blood stream somehow and caused the seizures. In any event, everything hurt: my chest, my arms, my ankle where there was an intravenous tube, my throat, my rear end. This time the incision ran from the center of the chest to under the right arm. But I was still among the living, although it didn't dawn on me then how important and miraculous that was.

I went home, started my high school senior year, but couldn't drive because I was on anti-seizure medication. There was fear that I could have a seizure while driving. My troubles weren't over yet, although I was no longer blue; instead, I turned yellow. I had contracted hepatitis from the blood transfusions. The pain in my abdomen from the swollen liver was bad. I got over that, continued my senior year and graduated. I now understand my family's tears at my graduation. I didn't then because I was 18 years old, feeling okay, and looking for a job before starting college.

My bout with the seizures concerned me and I had the idea that I was not capable of pursuing a rigorous field of study. I was always curious and analytical. My mother told me that I would either be a lawyer or blow myself up because I asked a lot of questions and I was generally mixing things together and loved fire. I thought that I would become a draftsman. I owe another debt of gratitude to the counselor who advised me that on the basis of my entrance test scores, I was capable of more. Thanks to my freshman chemistry teacher and the fact that I had a part time job in the chemistry laboratory, I decided I wanted to be an engineer. This was the era of Russia's Sputnik and the beginning of the space race.

I won't continue in detail, but I attended college, enjoyed life, and studied hard. Upon graduation with dual degrees in Chemical Engineering and Business, I moved from Colorado to Oklahoma where I met my wife of now some 43 years. We became the parents of two healthy and wonderful daughters who, in turn, have happy, successful marriages. From these marriages we have two sons. As the cycle of life continues there is now a granddaughter and a grandson. My career was satisfactory and I was able to provide a comfortable life for my family and perform the many tasks needed in an oil refinery, including climbing ladders and stairs that took me 60 to 100ft. above the ground.

I am now approaching my 68th birthday. The heart murmur and the arm to arm chest scar are now something I am proud of. I walk 2 to 3 miles per day at my wife's urging or ride my bicycle 10 plus miles; I can get my heart rate up with no problems followed by a quick recovery. My cardiologist gives me a stress test every couple of years and tells me I have the heart of a much younger man. Perhaps it's early life made it tough and resilient. It has learned to understand and appreciate love.

My family members who loved and supported me in my youth are all gone. Dr. Blount still lives in Denver. I called him recently to thank him for his knowledge and work that was a gift to me. Many people do not know how their actions touch the lives of others, and I wanted him to know. He, in turn, informed Dr. Swan's widow who later called me to ask if I would write this memoir to go along with her late husband's papers that will become part of a collection in the National Library of Medicine. She sent me a picture of the bathtub that was used in my two surgeries and is being placed in the Smithsonian Museum. AMAZING!

It is with great gratitude and honor that this memoir is presented as a tribute to those who gave and continue to give me the precious gifts of love, life, health, and happiness.